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DISRUPTING HEALTH AND SOCIAL CARE BY DESIGN

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ABSTRACT

In the UK, over six million people are unpaid informal carers for an ill, frail family member, or a friend who can't manage to live independently, or whose health or wellbeing would deteriorate without their help. This saves the UK taxpayer over £119 billion a year (Carers UK, 2011). Although the role and experience of informal carers is unique to their situation, it is known that their health suffers and that they have an increased rate of mental and physical health problems. This paper describes an on-going collaborative project between the first two authors and a carer organisation in Newcastle upon Tyne, England. The work presented here illustrates unique and innovative disruptive design interventions that re-imagine social and health care through participative design events. The paper will present some of the current findings from this on-going research and indicate how disruptive design innovation can support the development and delivery of radical future health and social care provision.

KEYWORDS: *Disruption, Design, Care, Interventions.*

BACKGROUND

There are an estimated 6.4 million people in the UK providing unpaid care and support to ill, frail and disabled friends and family members. Families provide the majority of care in the UK, outstripping social care services and private care providers combined. This contribution is worth an estimated £119 billion a year to the UK economy — more than the total cost of the National Health Service (NHS) in the UK. However, caring usually comes at great cost to carers. Many are forced to give up work to care, at the same time as they are faced with the considerable additional costs of disability. This means that, alongside the personal costs of ill-health, for many families, disability and caring pushes them into debt and hardship.

In England alone, around three million households contain an unpaid informal carer, which represents huge social care and NHS cost savings. The official figures from the 2011 Census show that there are over 25,000 adult carers living in Newcastle upon Tyne, which is almost 10% of the city's population. Although the role and experience of informal carers is unique to their situation, and caring can be a rich source of satisfaction, it is also known that their health suffers and that they have an increased rate of mental and physical health problems. Thus, it is very important that we identify informal carers so that we can provide much needed help and support. This paper will go on to describe support in the form of a series of unique and innovative disruptive design workshops that are helping Carers Centre Newcastle (CCN) re-imagine

their social and health care service through participative design events. The first two authors and care support workers at CCN believe the disruptive design approach, and the insights that have been revealed as a result have the potential to achieve more than the act of simply ploughing more money into social and health care could achieve.

WHO CARES?

In the UK, a carer is anyone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled, or has mental health or substance misuse problems. Anyone can become a carer; carers come from all walks of life, all cultures, and can be of any age. Many feel they are doing what anyone else would do in the same situation of looking after their mother, son, brother, or best friend, and just getting on with it. Carers experience many difficulties in their caring situations. For example, a carer could be someone looking after a new baby with a disability or caring for an elderly family member. In the UK, informal carers are the largest source of care and support. However, caring for a family member or friend is very demanding and can lead to a number of other related problems including:

- Carers facing a life of poverty, isolation, frustration, ill health and depression.

- Carers giving up a regular financial income, future employment prospects, and pension rights.
- Carers juggling several jobs with their caring responsibilities.
- Carers struggling alone not knowing that help is available to them.
- Carers' lack of access to information and financial support that is vital in managing the impact of caring on their own lives.
- Carers with multiple caring roles — often referred to as 'sandwich carers', who are frequently older women who care for relatives (e.g. a mother with dementia and a daughter who misuses drugs).

CARERS CENTRE NEWCASTLE (CCN)

Carers Centre Newcastle (CCN) opened in April 2004 in direct response to carers who had campaigned for seven years to have a place of their own in Newcastle City Centre. The campaigners wanted a setting that had no stigma attached to it, unlike a clinic or hospital. CCN originally operated as part of Newcastle Healthy City, but since 2004 has now become an independent charity and company limited by guarantee. CCN's vision is to improve the quality of carers' lives in and around the city of Newcastle upon Tyne and to work towards a future where Newcastle carers are recognised and valued, they are able to overcome inequality, receive support, information and advice, and are able to exercise choice and control through their caring journey and beyond, so that carers can balance their caring role and maintain their desired quality of life.

CCN offer award winning caring services that are confidential, non-judgemental, and impartial. They provide information, one-to-one carer support, training, and opportunities for carers to join groups or take part in events and activities as well as access sessions with CCN's complementary therapists and counsellors. The caring service process at CCN begins when a service user contacts CCN. At this point, one of CCN's Carer Support Workers will carry out a confidential assessment based upon the individual circumstances of the carer and the person they care for. At this stage, CCN may refer the carer to appropriate organisations for specialist services. Moreover, CCN provide carers with support in the format they are most comfortable with, which could be over the telephone, a home visit, a Centre visit, or by email.

However, against the backdrop of the failures of global financial capitalism (Bazzichelli & Cox, 2013), the widespread austerity measures and the quite sudden and dramatic general economic changes to the world in 2008, this has had a serious and significant impact on caring, carers, their families, and the work that CCN undertakes. Moreover, as changes occur to the population of Newcastle upon Tyne in terms of age, illness, disability, and diversity the number of carers will increase, as they will generally across the UK. The current austerity measures and diminishing budgets within health and

social care will reduce the number of people who are eligible to receive support and the move to deliver 'care closer to home' will increase the responsibility and reliance on carers. This is further exacerbated by the UK's on-going welfare reforms, changes in housing policies, employment and training opportunities, and other issues that all add up to a 'perfect storm' for carers.

THE DESIGN DISRUPTION GROUP

The Design Disruption Group is a small group of design researchers, educators, and practitioners whose collective objective is to bring about positive change via disruptive design acts. The group has been working together for over three years and has disruptively intervened in a number of contemporary situations in the private, public sector, and third sector. Example design interventions include projects such as 'sticker' campaigns on the streets of Edinburgh, 'fortune cookie' services for a Chinese restaurant in Gateshead, 'celebratory brass plaques' on the walls and alleyways of Newcastle, 'street lamppost data prompts' in conjunction with the Multiple Sclerosis (MS) society, a 'one week entrepreneur' project with the YMCA, and several others (see, <http://designdisruptiongroup.wordpress.com/> for more examples).

The on-going collaboration between Carers Centre Newcastle and the Design Disruption Group was established against the backdrop of some of the most challenging socioeconomic times that we have faced. Part of the rationale for this collaboration is that it will enable CCN to build a strong evidence base and depart from a reliance on anecdotal information or hearsay about what the real health and social care issues are. This evidence is paramount when making the case for carers to local and national decision makers. Health and social care providers repeatedly talk about the need to invest in 'prevention and early intervention' but struggle to move the budgets away from acute and critical services. Regional and national health and social care policy makers need to see real evidence of need, what can make a difference, and how it can or will work. Thus, the on-going collaboration seeks to contribute to discussions in Newcastle and elsewhere, to assist commissioners, local and national policy makers, and service managers to understand the benefits of investing in carers.

Initially, the Design Disruption Group held a series of workshops with CCN's staff members, including their Training and Development Manager, Carer Support and Development Workers, Information and Communications Co-ordinator, and Volunteer Counsellors. During these initial workshop sessions, CCN staff outlined what they wished to achieve from the collaboration. The key aim of the ongoing collaborative project is to help CCN continue to deliver an excellent service in the face of a number of exceptional circumstances including the widespread austerity measures, the increasing elderly population, and the increasing diversity and number of carers living in and around Newcastle upon Tyne, and diminishing budgets within health and social care. CCN's work is further exacerbated by the UK's on-going welfare reforms,

changes in housing policies, employment and training opportunities, and other issues that all add up to a ‘perfect storm’ for carers. The main aim for the first two authors (as two of the founding members of the Design Disruption Group) is to engage with real world issues and use design as a tool to enact real positive change. The Design Disruption Group in this project wish to utilise disruptive design interventions to ensure that all carers will receive greater choice and control in their lives as well as exploring the more general role that disruptive design interventions might play in improving the physical, mental health and wellbeing of carers, care support workers, and other stakeholders.

DISRUPTIVE DESIGN WORKSHOPS

The main aim of the disruptive design workshops is to break the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the health and social care of vulnerable individuals in the UK. Disruptive Design is an approach that the first two authors have developed over several years (Rodgers et al., 2011; Rodgers & Tennant, 2012; Rodgers et al., 2013). A disruptive design approach encourages the development of richer, more varied solutions to everyday issues by emphasising fun (Bisson & Luckner, 1996), ‘safe failure’, and doing things in ways that one wouldn’t normally do. In a disruptive design workshop, the emphasis is placed on having fun, relaxing, and trying things out in a stress-free environment where participants are encouraged to fail fast and fail often without fear.

In essence, the disruptive design workshops exploit techniques and approaches developed by the authors that provide opportunities for participants to experiment in a relaxed, stress-free environment with expert facilitators. Most of the research in public social and health care seeks to evaluate intervention effectiveness and value for money. In contrast, however, this work proposes to develop a series of disruptive design interventions and assess how they might improve carers’ lives in the North East of England. Given the extremely challenging nature of the informal caring situation in the UK, the main aims of the collaborative research are to:

- Help change society’s perceptions of caring in the UK through a series of disruptive design workshops and interventions (i.e. products, systems, services).
- Create a series of designed interventions that will help carers access support before they hit ‘crisis point’ when their health is sometimes irreparably damaged.
- Help identify the major day-to-day consequences of caring for people through the use of disruptive design techniques and approaches.
- Consider how prevention and early intervention (e.g. designed products, systems, services) could enable carers to have greater choice and control.
- ‘Formally invite’ carers to participate/collaborate in the creation of the designed interventions.

It is envisaged that this work will contribute to scholarly debates on how social design, innovation in general, and disruptive design innovation in particular can support the design, development, and delivery of health and social care services. This exceptional and important partnership between the first two authors and a third sector organization, established to represent the needs of carers in the North East of England, and to raise their concerns and issues nationally, offers a number of valuable opportunities for wider public engagement with the health and social care sector in the UK.

SOCIAL CARE BY DESIGN METHODOLOGY

This on-going work adopts an iterative, research-through-design mixed-methods approach where the first two authors and collaborating partner (CCN) are involved in the generation, collection, evaluation, and interpretation of both quantitative and qualitative forms of information. This approach has advantages over other research approaches particularly relating to the development of reliable explanations (Cresswell, 2003). Thus far, the work has utilized a number of research approaches and tools including participatory design workshops, carer surveys and care support worker interviews, and design probes (Gaver et al., 2004) during the collaborative activities with CCN. The participatory design (sometimes known as co-design) nature of this research has endeavoured to actively involve all stakeholders (e.g. carers, care support workers, policy makers, health and social care experts, citizens) in the design process of creating designed products, systems, and services that are intended to meet end users’ and other stakeholders’ needs and be ultimately usable. As such, this ongoing collaborative work seeks to address the following research questions:

- How can disruptive design interventions help ensure that all carers will receive greater choice and control in their lives?
- What role can disruptive design interventions (i.e. designed products, systems, services) play in improving the physical, mental health, and wellbeing of carers?
- Can disruptive design interventions support informal carers to have a life of their own outside of their caring role, including a social life, in work and education and training?
- Can disruptive design interventions contribute to ensure that carers do not suffer financially as a result of their caring role?
- Can disruptive design interventions ensure that carers are treated as expert partners in care?

The participatory design approach adopted in this project supports innovative ways of creating design interventions that are more responsive and appropriate to the end users’ cultural, emotional, spiritual, and practical needs. This approach is focused on collaborative processes and procedures of design that promotes user empowerment and democratization. In the research described in this paper, participants

(i.e. carers, service users, Carers Centre Newcastle care workers, and other relevant stakeholders) have been invited to collaborate with the first two authors during a series of innovative disruptive design sessions. The innovative disruptive design sessions have allowed the carers, service users, Carers Centre Newcastle employees, the first two authors, and other relevant stakeholders to collaborate during several stages of the innovative process. That is, everyone has participated during the initial explorations and defining the issues to be addressed, to help identify the key issues, and to focus potential ideas for interventions, during intervention development, and in helping evaluate any proposed design interventions. As such, the methodology proposed here is both highly innovative in the context of health and social care, and truly collaborative in nature.

A NEW MODEL OF CARE

Given the severe socioeconomic circumstances that CCN are being asked to work within, the first two authors set out to understand more about CCN's work and the key activities involved in providing health and social care. CCN are faced with an on-going crisis in that their award winning carer services are hugely over-subscribed and demand far outstrips supply. Their carer services are regularly assessed as 100% in terms of the service user satisfaction rates and this only adds to the clamour for their unique service. As each month passes, the number of enquiries that CCN receives increases significantly. Moreover, diminishing budgets within health and social care have reduced the number of people who are eligible to receive support and the move to deliver 'care closer to home' has increased the responsibility and reliance on carers. Coupled with national welfare reforms, changes in housing policies, employment and training opportunities, and other pressures all adds up to a 'perfect storm' for carers and carer service professionals in the UK.

As part of one of our initial disruptive design sessions with CCN, we asked their care support workers to 'Draw What CCN Does'. We suggested that this might involve them drawing a diagram or constructing a collage of images. We also suggested that the illustrations might be abstract or highly descriptive and that they should minimise the use of text in their illustrations and only use text if absolutely necessary. We also advised them that the images might focus on all of CCN's work or just on one aspect of CCN's day-to-day work. We provided the CCN staff with a series of pre-determined rubber stamps and ink and the majority of the participants utilized these in their drawing of 'What CCN Does'. A recurring theme in the participants' images was the concept of CCN as a 'transformational agent'. That is, the participants viewed CCN's role in the overall care service as one where the carers would receive support from CCN, be transformed via one or more of these services (e.g. 'trips out', 'relaxation', 'pampering', etc.), and then 'fly away' to get on with the rest of their lives.

CCN'S 'A TO Z CHARTER OF CARE'

As is commonly known, a manifesto is a public declaration of an organisation's policy and aims. In a political context, for example, a political party or political candidate typically presents their manifesto before an election. The origin of the word manifesto comes from the Italian 'manifestare', meaning 'make public', and 'manifestus', meaning 'obvious'. Similarly, a charter is a written grant by a country's legislative or sovereign power, by which an institution such as a company, university, or city is created and its rights and privileges defined. A charter, for example, can be a written constitution or description of an organization's functions. In a design context, manifestos and charters are fairly common phenomena (Danchev, 2011). A well-known example is *The Munich Design Charter*, published in Design Issues in 1991, signed by Dieter Rams and many of the other leading designers of the era. In that seminal paper, Rams et al. are well aware of design's responsibilities in all parts of contemporary life and as such *The Munich Design Charter* proclaimed that design must concern itself with '...economy as well as ecology, with traffic and communication, with products and services, with technology and innovation, with culture and civilization, with sociological, psychological, medical, physical, environmental, and political issues, and with all forms of social organization' (Rams et al., 1991).

Given the crisis in the carer service that CCN currently finds itself in, Rodgers and Tennant, as part of their disruptive design work, asked the CCN staff to write their own 'A to Z Charter of Care'. The intention of this activity was to help the CCN staff think more deeply about the service that they provide and also to help them 'professionalise' their service more. Like Rams et al.'s *Munich Design Charter* earlier, the tone of the CCN 'A to Z Charter of Care' is serious in its delivery and is intended to support the CCN staff articulate better their care service for the future years to come. Figure 1 shows the A to Z responses as created by the CCN team. The intention is to design and develop these letters further into finished pieces and hang them on the walls of CCN's new offices in Newcastle upon Tyne. As can be seen, CCN's 'A to Z Charter of Care' as



Figure 4. CCN's 'A to Z Charter of Care'

articulated by the care support workers themselves is: Aware – Befriend – Care/Control – Developing – Equality – Fresh – Give/Genuine – Helpful – Inspiring/Ideas – Judgement – Kick [problem] – Life – Mellow – Non-judgemental – Observe – Practical – Questioning – Radical – Structure – Time – Unusual – Very focused – Wonderful – eXciting – Yours – Zoned in. This simple disruptive exercise has actually revealed some significant aspects of CCN's work. In the A to Z above, there are some obvious responses such as 'care' and 'helpful', but there are others that have a much deeper meaning and resonate more with the crisis situation that CCN currently experiences, such as 'structure' (the need for more) and 'time' (the lack of).

CONCLUSIONS / OUTCOMES

This ongoing collaborative project between the first two authors and the CCN staff has delivered a number of positive outcomes thus far. First, the project has helped contribute to scholarly work on how disruptive design innovation can support the development and delivery of health and social care interventions in practice. That is, this work will lead to the production of a number of scholarly papers and articles for appropriate outlets that will increase the visibility of how design, as an instrument of change, can play a pivotal role in health and social care contexts, which will encourage further research. This article is just one of several planned for this ongoing research.

Second, the partnership between the first two authors and CCN has resulted in an application being made to the Arts and Humanities Research Council (UK) for a new collaborative doctoral student. The proposed PhD researcher will work closely with the CCN team members who have a strong reputation for their care provision and a proven track record in excess of fifteen years, and provide an opportunity to develop the primary research skills that are essential in a future doctoral graduate. CCN have numerous links with local, regional, and national bodies, and participate in many multi-agency initiatives that impact on carers and/or the people they care for such as Newcastle Council, Newcastle Acute Hospitals Trust, PROPS North East, and Barnardo's Young Carers. The opportunity for the PhD researcher to immerse him or herself in this research and practitioner network will be invaluable. The development of participatory design skills, the support of CCN's local, regional and national network, and an emphasis on developing disruptive design interventions for real world issues will build the skills necessary for the PhD researcher to undertake a successful academic or commercial career in the future.

Third, the project has helped establish an important partnership between Northumbria University and a third sector organization that will help represent the needs of carers in the North East of England and raise their concerns and issues nationally. The ongoing collaboration has also offered a valuable opportunity for a widening public engagement with the health and social care sector in the North East of Eng-

land. In so doing, the research has supported the missions of Northumbria University and CCN, and aligns with targeted priorities for public engagement identified by the Arts and Humanities Research Council (UK).

Finally, the ongoing collaboration will work towards a number of specific outcomes for both academic and public audiences in the form of scholarly papers, popular articles, web material, and community engagement sessions. The project will also strengthen the links between Northumbria University, CCN, and the larger regional knowledge community, which will help build a strong platform for future collaboration, research, and dissemination in the important area of how disruptive design interventions can support the development and delivery of health and social care in practice.

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